



# Quality of Care for Children with Special Health Care Needs: Medicaid Findings from the CAHPS® Child Survey

## Introduction

Identifying and measuring the quality of health care for children with special health care needs is an increasingly important objective for State Medicaid, SCHIP, and Title V programs. Reasons to be concerned about this population include the following:

- These children have more complex health care needs than do children without special needs.
- The majority of public and private health care dollars spent on children goes to caring for this population.<sup>1</sup>
- Federal mandates require Medicaid and SCHIP programs to identify children with special health care needs, monitor their access to certain services, and collect specific performance measures for them.<sup>2</sup>
- There is a growing body of evidence that children with special needs often experience inadequate care.<sup>3</sup>

This fact sheet presents key findings on the quality of care received by children with special health care needs as measured by the CAHPS Health Plan Survey for children (referred to here as the CAHPS Child Survey). The data presented here come from an analysis of survey results from 10 States that administered the Medicaid version of the CAHPS Child Survey in 2002. These data shed light on the prevalence of children with special health care

## Who Are “Children with Special Health Care Needs”?

Children with special health care needs are *“those who have a chronic physical, development, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”*

Source: McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. *Pediatrics*. 1998;102:137-140.

needs in the Medicaid population, and some of the ways in which their experiences with care differ from those of children without special needs, specifically in the areas of getting needed care, access to prescription drugs, and access to specialized services. This fact sheet also provides information on how States can obtain and use the CAHPS Child Survey and other data sources to assess the quality of care for children in their programs.

<sup>1</sup> Lewit EM, Monheit AC. Expenditures on health care for children and pregnant women. *Future of Children*, David and Lucile Packard Foundation, 1992. 2, 95-114.

<sup>2</sup> Kaye N, Curtis D, Booth M. *Certain Children with Special Health Care Needs: An Assessment of State Activities and Their Relationship to HCEA's Interim Criteria*. Washington, DC: National Academy for State Health Policy, June 2002.

<sup>3</sup> Bethell C, Lansky D, Hendryx M. *The Robert Wood Johnson Foundation National Strategic Indicators Survey: RWJF Priority and Program Area Performance Indicators Summary Report*. Portland, OR: FACCT-The Foundation for Accountability, September 2000. Also see: Bethell, C. *Measuring patient centered care across consumer relevant domains of quality: A report prepared for the Institute of Medicine Committee on the National Quality Report on Health Care*. July 2000.

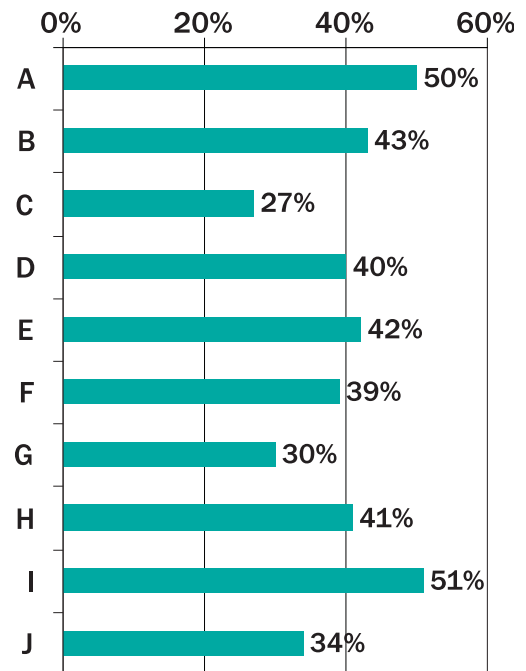
## Key Findings from the CAHPS® Child Survey

### ***The Proportion of Children with Special Needs Surveyed Varies by State***

Figure 1 shows the percentage of respondent children in each of the 10 States who the CAHPS Child Survey identified as having a special health care need. The large variation in the percent of children identified as having special needs is almost certainly due in part to differences in State program structures or in the populations surveyed. For example, the CAHPS Child Survey identifies approximately 21 percent of children in the general Medicaid population as having special needs (i.e., 21 percent screen positive). In contrast, 95 percent of children in the Medicaid SSI population screen positive.<sup>4</sup> National statistics indicate that, in 2000, 16.2 percent of all children had special health care needs.<sup>5</sup>

Those States that administered the survey to a population known to have more complex conditions will necessarily identify a higher population of children with special needs. For example, some States use a sampling methodology that oversamples for children in certain eligibility groups that are more likely to

**Figure 1.**  
**Percentage of Children with Special Needs by State**



screen positive. These differences highlight the importance of considering sampling methodologies when interpreting variations in results by State.

## About the CAHPS Child Survey

CAHPS is an evolving family of survey instruments and reporting tools designed to measure important dimensions of health care performance from the consumer's point of view. It is sponsored by the Agency for Healthcare Research and Quality (AHRQ) and developed in partnership with the Centers for Medicare & Medicaid Services (CMS) and private research organizations.

The CAHPS Health Plan Survey for children (known as the CAHPS Child Survey or Child Questionnaires) can be used to gather information from parents or guardians about the experience of care for their children aged 17 or younger. It consists of a set of core questions, a set of items for children with chronic conditions, and optional supplemental items.

### **The Children with Chronic Conditions (CCC) set**

consists of a series of items used to identify children with special health care needs (known as the **screener questions**) and 31 questions related to the following major topics:

1. Access to prescription medicines
2. Access to specialized services
3. Family-centered care
4. Coordination of care and services

**To learn more** about CAHPS surveys of patients' experiences with health care and the Children with Chronic Conditions set, visit the CAHPS Survey Users Network Web site (<http://www.cahps-sun.org/>).

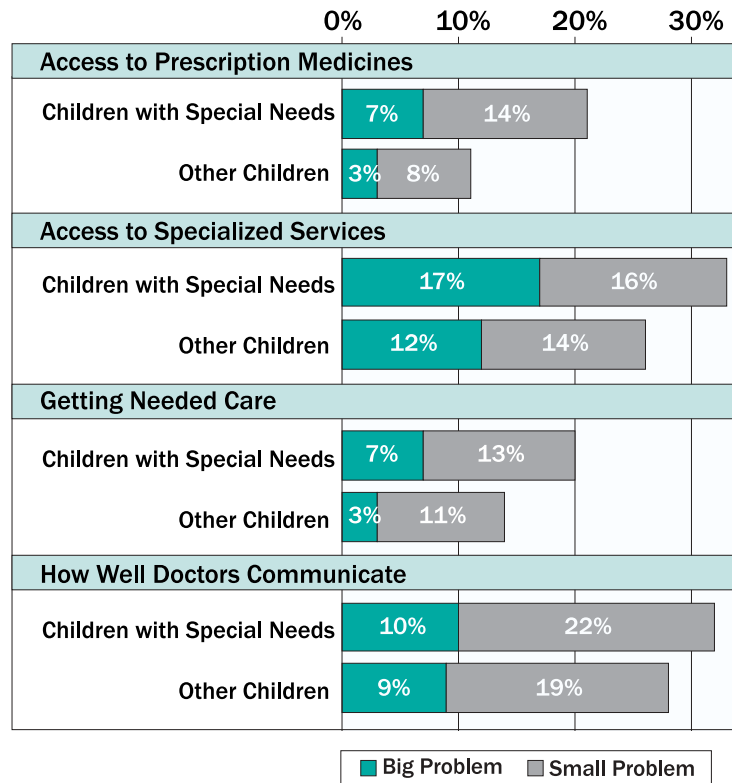
## Children with Special Needs Have Different Experiences with Care

Figure 2 highlights the different experiences of children with and without special needs as indicated by four CAHPS measures:

- Access to Prescription Medicine
- Access to Specialized Services
- Getting Needed Care
- How Well Doctors Communicate

This analysis suggests that, across the 10 States, differences in the experiences of children with special needs and other children are more pronounced in the areas pertaining to access. Differences in the experiences of these two groups are not as large in the area of doctor communication.

Figure 2. Percentage of Children Reporting a Problem



<sup>4</sup> Bethell CD, Read D, et al. Identifying children with special health care needs: development and evaluation of a short screening instrument. *Amb Pediatrics*. 2002;2(1):38-48.

<sup>5</sup> Dougherty D, Chevarley FM, Bethell C. "Quality of Care for Children with Special Health Care Needs: Data from a Nationally Representative Survey." Presented at the AcademyHealth Annual Research Meeting, June 2003. To be published.

The **screener questions** ask about the following five health consequences:

1. Use or need of prescription medication;
2. Above average use or need of medical, mental health, or education services;
3. Function limitations compared with others of the same age;
4. Use or need of specialized therapies (e.g., occupational therapy, physical therapy, speech); and
5. Treatment or counseling for emotional, behavioral, or developmental problems.

### Data and Methods Used in this Analysis

The analysis in this fact sheet is based on data obtained from the National CAHPS Benchmarking Database (NCBD), which is the national repository for CAHPS survey results. CAHPS survey sponsors submit data to the NCBD, which produces customized benchmark reports as well as data for research purposes.

**Case-Mix Adjustment:** Data from the 10 State Medicaid programs that submitted 2002 CAHPS Child Survey results were adjusted for the age and education of the parent/guardian and for the child's health status as reported by the parent/guardian. Case-mix adjustment ensures that differences in results are not due to differences in these factors.

## States Differ in Results for CAHPS Measures

The data presented in this fact sheet summarize differences in quality of care as measured by the CAHPS Child Survey across all of the States that participated in this analysis. However, results actually vary fairly significantly from State to State. For example, for the “access to specialized services” measure, the difference in the percentage reporting a problem ranged from -2 percentage points in one State (i.e., a smaller percentage of children with special needs reported a big or small problem) to 12 percentage points in several other States.

In addition, States varied in the total percentage of respondents (i.e., those with and without special needs) reporting a problem. The total percentage reporting a problem with access to specialized services, for instance, ranged from 23 percent in one State to over 38 percent in another. These data may reflect differences in States’ sampling strategies (i.e., how they selected which children to survey). The discrepancies suggest a need for States to explore further the reasons for differences in quality and design interventions that address the issues pertinent to their populations.

## Resources for Implementing and Using the CAHPS Child Survey

### CAHPS Survey Users Network (SUN)

The SUN distributes all CAHPS-related products and provides extensive guidance to support users in planning and implementing a CAHPS survey project and reporting and disseminating results. Free technical assistance is also available.

To learn more about CAHPS surveys, visit the SUN’s Web site: <http://www.cahps-sun.org/>. For information on the questionnaires for children, select “Products,” then “Health Plan Survey.”

To contact the SUN directly:

- Send an email to [cahps1@westat.com](mailto:cahps1@westat.com)
- Call the SUN Help Line at 1-800-492-9261.

### National CAHPS Benchmarking Database

The NCBD facilitates comparisons of CAHPS results among different sponsors, including Medicaid agencies, SCHIP programs, public and private employers, and individual health plans. The NCBD currently contains 6 years of data from CAHPS. Further information about the NCBD is available through the NCBD Web site at: <http://ncbd.cahps.org/Home/index.asp>

### The Child Health Toolbox

The Child Health Toolbox is an online resource designed to help State and local policymakers, program directors, and staff learn about measuring quality of health care in child health programs. See <http://www.ahrq.gov/chttoolbox/>.

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## Other Sources of Data on Quality of Care for Children

### Medical Expenditure Panel Survey (MEPS)

Since 2000, MEPS has collected data on experiences of care for all children with special health care needs. MEPS results in *Statistical Briefs* #3 and #12 as well as the data are available at: <http://www.meps.ahrq.gov/PrintProducts/PrintProdLookup.asp?ProductType=StatisticalBrief>.

### National Survey of Children with Special Health Care Needs (CSHCN)

The National Survey of CSHCN is a module of the State and Local Area Integrated Telephone Survey (SLAITS), sponsored by the National Center for Health Statistics of the Centers for Disease Control. A total of 196,888 households participated in this survey between October 2000 and April 2002. For more information, see <http://www.cdc.gov/nchs/about/major/slaits/cshcn.htm>.

### National Healthcare Quality Report and National Healthcare Disparities Report

Released in December 2002, these two reports represent the first national comprehensive effort to measure the quality of health care in America as well as differences in access and use of health care services by various populations. See <http://www.qualitytools.ahrq.gov>.

### AHRQ’s Child Health Program

For more information about AHRQ’s child health care initiatives, please contact:

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